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ABSTRACT

Whether individuals should be allowed to see and correct their health records evokes controversy that revolves about citizens' rights to know what information is kept on them, society's duty to protect individuals' and doctors' rights, and the rights of employers and other parties to maintain the confidentiality of their files. A review of the viewpoints of health professionals, the current laws and regulations attending to the controversy, and major organizations and issues that prompt debate of the topic creates the appearance that there is no consensus on the wisdom of granting individuals access to their medical records. Whether or not medical record access for individuals becomes a concrete privilege, it promises to serve as a controversial stepping stone for the discussion of other rights among consumers. (RL)

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FREEDOM OF INFORMATION CENTER REPORT NO. 412

ACCESS TO PERSONAL MEDICAL RECORDS

This report was written by Sharon Weisenstein, a recent graduate of the University of Missouri School of Journalism.

A middle-aged man employed by a major automobile manufacturer knows he is in line for a promotion. But the promotion doesn't come. Since his performance in the job is exemplary, he suspects something is amiss. He decides to check the company's file on him. There, in his medical record, he finds information indicating he suffers from heart trouble. But his heart is healthy, and he has never been a patient of the physician whose report appears in his file. Unknown to him, however, this report has influenced the company's decision not to promote him. After confirming the error, he is able to remove the report from his file and enhance his chances for job advancement.

A young woman who successfully recovered from a mental illness several years earlier feels a need to recall and reconstruct the experiences she had while under treatment. She goes back to the hospital where she had been a patient and asks to see her complete file. Sitting in the institution's library, leafing through reams of notes made by physicians and psychiatrists in her case, she is able to piece together the events that eventually led to her recovery.

Access to personal medical records can be important to people in a variety of situations. The above examples illustrate how the opportunity to examine such records can result in the discovery of false or irrelevant information or the satisfaction of a psychological need.

Reasons for inspecting personal medical records are plentiful. However, opponents of access regulations have their share of arguments, too. Major conflicts seem to center on the citizen's right to know what information is kept on him, society's duty to protect individuals and the rights of doctors, employers and other parties to maintain the confidentiality of their files.

Some Perspective

The Privacy Act of 1974, which applies to all federal health-care facilities, provides, in part, that a patient or his representative may inspect or copy the patient's treatment record. But the access rule here comes complete with a "laundry list" of exceptions. And it applies only to personal records of the executive branch of the federal government about individuals, not to state and local government records or those of private state and local organizations.

Some state facilities are required by law to grant patients access to their health records. Fifteen states have established regulations guaranteeing patients direct access to at least some of their medical records. But, as with the federal policy, loopholes abound. Some state laws, for example, permit individuals to see their records, but not to enter a "statement of disagreement" if they object to information recorded there.[1] (Only the federal government and a few state governments are legally bound to make changes in a record or enter an individual's dispute when he challenges information. Even then, an error usually must be documented before a correction will be considered.)

Most private hospitals and clinics are not subject to laws requiring them to give patients access to their records. Hospitals generally develop their own policies on medical records.

Although few laws exist requiring doctors to make their patients' records available to them, more and more doctors are beginning to believe there are benefits in allowing patients to see what is in their file. New York recently passed a rule giving patients the right to see their doctors' files on them.[2] But reservations accompany this kind of access policy: Many doctors fear that seriously ill patients or those under psychiatric care will exaggerate the significance of what they read in the record. Some patient-access rules stipulate that, if a doctor thinks information in a record may have an adverse effect on a patient, he may entrust it to an "agent" — a family member or someone with a medical background — who can relate to the patient those portions that are in his interest.

While the terms "medical record" and "health record" often are used to mean the medical history report kept by a person's physician or other health professional, they may refer to any document containing information about a person's health. There are at least eight kinds of "health records" not directly connected with treatment: those kept by insurance companies (firms dealing in life and health insurance, and government insurers), employers, credit bureaus and grantors, schools, law enforcement agencies, researchers, welfare departments and government agencies. The National Bureau of Standards has pointed out that information contained in medical records belonging to doctors and hospitals is widely shared with these other parties.[3]

Summary: Whether an individual can or should be allowed to see and correct his health records evokes controversy in the medical and business worlds and among private citizens. This report will examine the viewpoints of health professionals, describe current laws and regulations and look closely at a few major organizations and issues that prompt debate.

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Insurance companies need to know what medical problems their applicants have in order to determine risk, and what conditions their policyholders have and how they are treated so when a policyholder applies for reimbursement, the companies can validate his claims. Employers are interested in an employee's or potential employee's job fitness and in health conditions that might affect his later work ability. If a job exposes workers to toxic substances or other health hazards, an employer is required by law to keep records of any medical problems that could be work-related. And in general, companies with 11 or more workers are expected to keep records of occupational injuries and illnesses.

State governments keep records of the medical circumstances of all births and deaths. And many states require physicians to report abortions, cancer, venereal diseases and other illnesses. Most of the information gathered by government is for research, planning or regulation.[4]

In the course of collecting and sharing medical information, more data than is needed for designated purposes often is accumulated by third parties. "It is important to prevent the use of irrelevant health information in employment or promotion decisions," warns the National Commission on Confidentiality of Health Records.[5]

To reduce the chances of being hurt by the circulation of incorrect or irrelevant information, individuals should check their medical records every two years, a **Business Week** writer advises.[6]

Federal Laws

Access to medical records on the federal level is governed by the Privacy Act, which was adopted to tighten confidentiality of personal records and provide individuals access to their own records as well. The act gives persons in federal facilities the right to inspect and copy all but certain portions of their records containing testing and evaluation materials and open investigative records. Records held by military and Veterans Administration hospitals, public health service facilities and other federal institutions are included. Federal agencies covered by the act include executive departments and offices, military departments, government corporations, government-controlled corporations and independent regulatory agencies.

A 1977 report by the Privacy Protection Study Commission (a creation of the Privacy Act) recommended that both federal and state laws be adopted recognizing the right of "an individual who is the subject of a medical record maintained by a medical-care provider or another responsible person designated by the individual to have access to the medical record."[7] This also would provide the opportunity to review and copy it.

The commission also recommended that procedures governing correction of a record be established. When a patient requests a correction, the health-care provider must, within a reasonable time, make the correction or inform the individual of its refusal to do so and why. A patient must then be told of the procedures for appeal. Under the Privacy Act, if an appeal is denied, the person may file a statement of disagreement to be added to the record.[8]

But the act is not as effective as it might be. "You can drive a truck through the Privacy Act," says NCCHR counsel Robert Belair of the act's thinness.[9]

Loopholes in it and the need for other kinds of provisions on the federal level have prompted the proposal of other regulations to give citizens greater access to their medical records. A bill introduced in the House more than a year ago would require all private institutions participating in the Medicare and Medicaid programs to allow patients to inspect, copy and correct their medical records on request. Statements of disagreement would be permitted in cases when the institution refuses to allow amendment. This law would not cover patients at federal hospitals since they already have a legal right of access under the Privacy Act.[10]

State Laws

As previously noted, about a third of the states have laws providing some form of direct personal access to medical records. Many of these statutes are limited; virtually none allows unrestricted access. The laws vary in coverage: perhaps applying to hospital records but not doctor records; in the exemptions they allow; in who has access — the patient himself or a representative; in the form of access, such as whether the patient can copy or only see the record, and in prerequisites to access. About a half dozen states provide for indirect access (by an individual's attorney or other representative).[11]

Yet about half the states have no provision at all for individual access to personal medical records.

In **Colorado**, the law provides that all patient records be made available to the individual or his representative "at reasonable times and upon reasonable notice." The statute, however, does not apply to doctors' office notes.[12]

Former patients in **Connecticut** may inspect and copy their hospital records. But they cannot see medical information about them kept in credit files.[13]

District of Columbia law provides that public hospitals must release a patient's medical record to his attorney or physician upon the patient's written authorization.[14]

A **Florida** statute permits access to doctors' records, and hospitals must now furnish copies of medical records (except psychiatric or consultation reports) upon request by patient or his representative.

In **Georgia**, state hospital records may be released to physicians, attorneys and government agencies on the patient's request.[15]

Hawaii's law provides that copies of records be made available to a patient unless his health-care provider believes that the person's health would be harmed by seeing them. In that case, copies of the records must be given to the patient's attorney if the patient authorizes it.[16]

Illinois law requires most public and private hospitals to provide copies of hospital records to former patients, their doctors or attorneys.[17]

In **Indiana**, a patient and those to whom he gives written permission may see his hospital records; this statute, however, does not apply to physician records.[18]

A **Kansas** confidentiality statute contains an exemption allowing disclosure of a patient's record to him with his written consent. But a treatment facility can refuse to let him see portions of the record if it is believed disclosure would be detrimental to his welfare.[19]

According to **Louisiana** law, both patients and their doctors may request copies of treatment records, but only from public hospitals.[20]

The law in **Maryland** states that medical files maintained by insurance companies for life or health policies must be made available for inspection. But information a physician provides for these files can be withheld for five years after the date of a medical examination.[21]

A bill passed in 1977 gave mentally retarded persons in **Maryland** the right to inspect, copy and amend or supple-

ment their medical records and to prohibit most disclosures to third parties.[22]

Individuals in **Massachusetts** can get their medical records from most sources except credit files. They have a right to see their full hospital records, but the same absolute right does not extend to records kept by a physician.[23]

Patients in **Minnesota** may obtain "complete and current information possessed by that provider [of health care] concerning any diagnosis, treatment and prognosis of the patient in terms and language the patient can reasonably be expected to understand." Copies of various records or portions of them must be provided on written request. If a provider believes disclosure might harm the patient physically or mentally, the information may be given to a third party.[24]

In **Nevada**, "each provider of health care shall make the health-care records of a patient available for physical inspection" by a patient or his representatives. If copies are desired, the provider must supply them at reasonable cost, a common condition for disclosure in many states.[25]

Patients have access to their doctor's records, under a **New York** regulation. But the doctor may restrict access if he believes disclosure may adversely affect the patient's health.[26]

An **Oklahoma** statute gives patients the right to obtain copies of all their medical records except psychiatric records.[27]

Oregon recognizes the right of an individual to review his medical records held in public agencies and publicly operated institutions. The statute exempts the disclosure of psychiatric and psychological information, which may be withheld to avoid interference with the treatment.[28]

The Commonwealth Court of **Pennsylvania** decided in February to give patients in Pennsylvania access to their hospital medical records under regulations of the Pennsylvania Department of Health. One portion of the regulations says that a hospital "shall provide the patient upon request access to all information contained in his medical records, unless access is specifically restricted by the attending physician or is prohibited by law." Procedures are being developed that would require a patient to sign a written request to see his records.[29]

Utah law provides that confidential hospital records may be copied by a patient's attorney.[30] In all states, lawyers may request medical records on behalf of a client. Says Ted Bogue, a staff attorney with Ralph Nader's Health Research Group, "The hospital or doctor does not have to give it [your medical record] to you if you ask. But they have to give it to your lawyer."[31]

Virginia and **Ohio** passed laws in 1976 allowing an individual to inspect and challenge information about him in government files.[32] In **Virginia**, the law provides for access to a patient's medical records by the patient or his attorney. But mental health records may be withheld if the treating physician objects to disclosure.[33]

Legislatures in **California**, **Ohio**, **Wisconsin** and **Missouri** were planning to consider this year granting individuals access to their doctors' records.[34]

The law in **Missouri** gives doctors the right to withhold a patient's record on the basis of his belief that seeing charts would be detrimental to a patient's progress.[35]

State and local government employees sometimes have access to their files under state privacy acts and/or state Freedom of Information laws. Civil service employees may have access under civil service regulations, and union employees under union contract provisions. Some states, such as **North Carolina**, have a public employee record law that gives employees the privilege of correcting or supplementing their records. Medical records, however, are commonly exempted under such laws.

Inherent in many state and federal privacy and FoI laws is the right of access. Without the opportunity for an individual to see and correct his records, he cannot knowledgeably protect his privacy. He needs to know what his record contains before he consents to disclosure to a third party — or so some privacy laws imply.

While many states have no statutes granting access, none of them have laws denying it. And health-care providers are always free to allow their patients access.

But in most states, the Health Research Group noted, "it is much easier for patients to get their CIA or FBI files than to get their medical records."[36]

While more and more states are opening up medical files to individuals, the majority still make no provisions for such access. And those laws that exist on state levels contain conditions and exceptions that make it easy for doctors, hospitals and other parties to withhold information.

The Professionals' Views

Opinion in the medical world over patient access to records is changing; nevertheless, some doctors and officials of medical institutions hold tenaciously to the belief that showing charts to patients invites problems.

Traditionally, health professionals have assumed that medical records belong to them rather than to the patient, that confidentiality means that patients, as well as others, are excluded from seeing their files and that a patient must place a high degree of trust in his doctor in order to be helped. Now these concepts are being challenged.

In a discussion of patients' access to psychological test reports, which are considered part of "medical records," William H. Smith writes, "No persuasive evidence that patients have been harmed by reading their own medical records can be marshaled."[37]

Yet he acknowledges two sources of potential harm to a patient: misuse of the knowledge contained in a record and impairment of a patient's trust in his clinician.[38]

Pros and cons on both sides of the issue have been noted by Budd N. Shenkin and David C. Warner in the article, "Giving the Patient His Medical Record: A Proposal To Improve the System." Among the benefits they cite to granting access are:

- A patient receives more complete information
- More patient cooperation, since the written record helps a patient remember and understand the reasons he should comply with doctor's orders.
- Better records because the patient is allowed to make corrections. The patient also will be more likely to keep relevant notes of his symptoms for the next visit.
- It serves as an educational tool.
- If a patient obtains a copy of his medical record, he does not need to rely on a faulty memory when giving health data to another doctor or hospital; he may avoid being subjected to repeated testing to learn information available from his medical record.
- An individual may have a better basis for choosing or changing doctors; he is better equipped to make judgments about health professionals and distinguish the good from the bad.
- More guides to medical care will be published, thus helping individuals understand their health problems and take an active part in their health care.

Arguments presented against patient access include the

following:

- Records may be falsified by patients.
- The obligation to keep a record that patients will read may burden doctors.
- So much disclosure could lead to malpractice suits.
- Critical patients may use their medical record to find fault with a doctor or institution.
- Patients may increase self-treatment.[39]

The American Medical Association favors the exercise of discretion by the doctor in releasing to patients their medical records:

> It is our position that the right of a patient to medical information from his physician is based upon the fiduciary relationship which imposes a duty to act in the best interest of the patient. It would be a violation of that duty to provide information which would be harmful to the best interest of the patient as a matter of sound medical judgment. It is our position that a physician has both a right and a duty to withhold information in circumstances in which he reasonably determines that it would not be in the best interest of the patient.[40]

The AMA states in its **Opinions and Reports** (Section 9, paragraph 4) that

> The Principles (of Medical Ethics) neither intend nor require that a physician give a copy of these records to his patient. These records are primarily the physician's own notes compiled during the course of diagnosis and treatment so that he may review and study the course of the illness and his treatment. The records are medical and technical, personal and often informal. Standing alone they are meaningless to the patient but of value to the physician and perhaps to a succeeding physician. The patient, however, or one responsible for him, is entitled to know the nature of the illness and the general course or regimen of therapy employed by a physician. The extent to which the physician must advise his patient may be limited by the nature of the illness and the character of the patient. The physician in advising his patient must always act as he would wish to be treated were he in a like situation.[41]

And when confronted with the question of an access law for patients, an AMA official said that:

> this could result in numerous cases in inappropriate disclosure of medical information. For example, certain individuals, upon seeing their medical records, might decide to treat themselves. Other individuals might be unable to cope with learning about a terminal illness. Individuals with psychiatric problems could be seriously harmed by learning of information in their medical records.[42]

Studies done in recent years have led some health professionals to recommend that patients receive a copy of their medical records.

After a seven-month study to assess the effect of giving patients copies of their admission evaluations and discharge summaries, doctors at the Medical Center Hospital of Vermont reported that patients generally reacted positively. "We could identify no instance in which a patient was harmed by being offered his record. It seems likely that patients are better able to handle information than we usually assume."[43]

The hospital had been giving records to all inpatients in its Rehabilitation Medicine Service since 1972. The practice was begun to improve patient education, to give patients more opportunity to contribute to the planning of their care and to increase the staff's accountability to patients.

The staff examined medical, social, psychological and environmental problems involved in the record-sharing practices during the seven months of the study. Four evaluation methods were used. Nurses discussed each person's record with him and reported on his reactions. Notice was taken of whether doctors modified the content of any records as a result of knowing patients would see them. Each discharged patient was asked to fill out a questionnaire about his reaction to the "education program." And the medical team discussed together how sharing the records had altered their work with patients and how the access policy affected the hospital unit.

Among the findings were an increase in the use of simple words in the records and explanations by doctors of some technical language. Doctors modified the content in about 10 percent of the records, but only language was changed (for instance, "cancer" replaced by "tumor"). Doctors never withheld factual information or avoided listing a problem.

Of the 125 patients involved in the study, half made some correction or addition to their records when given the opportunity, and 60 percent asked a question on vocabulary or meaning.

When given a choice of several different methods of access, 72 percent of the patients said they preferred a copy of their official record. Twenty-two percent asked for a summary letter from their physician instead. Four percent said they would rather just discuss the information with a health professional.

The staff reported more freedom in interacting with patients. They noted a shift in relationships from "paternalistic and caretaking" to "collaborative and educational." Nurses said they believed record-sharing improved the quality of health-care teaching.

Patients in the study used the records to explain themselves to their families. "And inclusion of emotional and sexual issues on the problem list facilitated discussion of problems important to the patient."

The researchers suggested that the type of access used contributed to the success of the experiment. "The fact that the report was a carbon copy of the hospital record was interpreted as a declaration of openness and trust."

Other comments made in evaluation showed optimism about patient-record access and its potential:

> Record-sharing is a tool that may serve to improve patients' satisfaction with their medical care. It may increase the ability of patients to care for themselves and to move about within the med-care system in an orderly way. It may prove to be one form of audit for quality and efficiency of care.
>
> We conclude that giving the patient his record is a safe and inexpensive aid to the rehabilitation process, and is probably mandated by the changing relationship between professionals and their clients, and by the patient's need to negotiate his own health care in an increasingly complex and mobile society.[44]

A 1971 study at the University of Vermont's Given Health Care Center had also suggested that a patient's involvement in audit of his record could be valuable. Patients were asked to review their patient profiles and subjective data under problem listings to check them for accuracy, and to review the treatment plans to make sure they understood them.

To assess patients' reactions to this procedure, questionnaires were sent to 100 consecutive patients who had received

complete examinations and copies of their records. A form for comments and corrections accompanied each questionnaire.

Of the 93 persons who responded, 97 percent indicated they felt less anxious about their health after seeing their record. Two patients reported increased worry over their health, however. Eighty percent indicated they were more careful about following specific recommendations for medications than they were prior to record reviewing; 78 percent indicated they had made changes in their pattern of living, eating or drinking after reviewing their record.

The researchers explained, "It is our philosophy that the medical record belongs to the patient and that he has a right to all of the information within it." They cited the no-cost audit function of the patient who reviewed his record as a beneficial side effect of the record-sharing.[45]

Beth Israel Hospital in Massachusetts completed a similar study last year. The two-year experiment had consisted of giving patients their full medical record on request. They found that patients who took advantage of the offer "appreciated the sense of trust and credibility that is symbolized by sharing the medical record," said nurse-practitioner Ruth Fischbach.

Results of the access policy in that study included better cooperation on the part of patients, more carefully written and more objective medical records and the exchange of information "that may alter therapy toward a more realistic course."

Ms. Fischbach said the staff was reluctant to show patients records that contained phrases like "seductive manner" and "appears to be a drug user." "But the patients have handled it well," she said. "And sometimes it has resulted in our learning something significant about the patient."

Only about 10 percent of patients request access to their record, according to Ms. Fischbach.[46]

Some less positive findings were reported in 1977 by a team of researchers at Australia's Royal Melbourne Hospital. When a control group and an experimental group were compared, they found no significant differences between those patients who received their medical record and those who did not with regard to several factors. However, "in individual instances access to the hospital record seemed to facilitate communication and provide an opportunity for hospital inpatients to monitor objectively . . . "

The five-month study looked at the effect of exposure of acutely ill patients to their problem-oriented records, the effect of the policy on doctor-patient communication, the policy's acceptability to patients and health-care personnel and the feasibility of such a policy in an inpatient setting.

No real differences between the control and experimental groups were found in their ability to recall medical problems and medicines at discharge; little difference was found in change between admission and discharge scores of self-reported depression, anxiety and contentment, attitudes toward staff, hospitals, medication, illness and self.

In some instances, patients' understanding was hindered by medical abbreviations, vocabulary and handwriting in records. Some doctors were forced to alter their bedside style of communication as a result of patients seeing the records. And the researchers reported that "many patients were unable to cope with the record for practical reasons such as intelligence, language difficulties, or their infirmity; others did not wish to part with the emotionally protective convention of leaving the interpretation of their illnesses to their doctors."

But physicians claimed record-access resulted in more discussion than if the doctor controlled the release of information on the patient's condition. They also reported discussions of terminology prompted by review of the record. The record was cited as the chief constant source of information.[47]

Although hospitals generally develop their own policies on access to medical records, the common rule is to allow patients access to only those portions of their records not considered harmful.

In Pennsylvania, however, the state court recently ruled that hospitals must give patients access to their medical records. But doctors may monitor the disclosures. Even if they refuse their access, though, a patient still can see his record if he signs a waiver stipulating that he:

- knows and accepts the fact that the records are best interpreted by a physician.
- recognizes the possibility that he may be damaged emotionally or physically by the effect of seeing the records.
- acknowledges that his viewing of the information may inhibit the doctor's treatment.
- accepts the record as hospital property.

The Hospital Association of Pennsylvania opposed the regulation at first because it feared an increase in malpractice suits. But when the waiver idea, already successfully used at St. Francis Hospital in Pittsburgh, was proposed, the association relented.

Patients in Pennsylvania had frequently complained that hospitals were reluctant to let them see their records and charged excessive amounts for copying. The new regulations ensure that copies will be provided "at reasonable cost."[48]

Mental patients have the toughest time getting access to their medical records. William H. Smith notes that a psychologist is not required to give a patient his written record. Few psychologists or psychiatrists feel it is possible to write a report on a mental patient that is complimentary.

"Even the gentlest interpretations offered before a good working relationship is established can have a stinging, assaultive effect upon the receiver," Smith says. He cited the case of one teenage girl who stole her test report from a nursing station, saying, "How could that nice old man say such nasty things about me?"[49]

Smith goes on to say:

> To see in black and white his exact I.Q. scores or to read diagnostic labels such as "schizophrenia" or "inadequate personality" could certainly be of no constructive use to the patient, and to read descriptions of latent or tenuously defended against characteristics and tendencies could be nothing but upsetting.[50]

If a mental patient is allowed to see his test results, Smith says, the doctor usually tries to write them in language that is easy for the patient to understand — but superficial.

The main concern of professionals in refusing access to mental patients is that of avoiding unnecessary anxiety. But some people say that withholding records might create more anxiety for mental patients than providing access would.

Smith tells of cases in which the content of psychological test reports has been effectively used in treatment and in diagnostic processes preparatory to treatment. In one instance, a psychiatrist reviewed with a patient his test report from a psychologist, "translating" it into simpler language. "The patient got a great deal out of this session," he reported. "At several points, he said, 'I will have to think more about that' or 'This is something I would like to work on.' "[51]

Since mental health records often are kept for many years after discharge, the opportunity for mental patients to ex-

punge information that they believe to be wrong or irrelevant can be especially crucial.

Medical Information Bureau

A non-profit trade association with more than 700 member insurance firms in the United States and Canada keeps computerized records on about 11 million people.[52] This group, the Medical Information Bureau, has come under attack by consumer, civil liberties and Congressional spokesmen for alleged secrecy and the kind of data it keeps in its records.

The MIB exists to allow insurance companies belonging to its data bank system to obtain information on individuals applying for policies. (The bureau, however, has files on less than 10 percent of all citizens who apply for life insurance.[53]) Information contained in these records, 95 percent of which is medical, is used by insurers to determine whether a person would be a good insurance risk. The MIB states that it contributes to lower underwriting costs and thus helps lower premiums for consumers.

The group dates back to 1890 when a group of domestic life insurance medical directors started the "Rejection Exchange." This organization informed members of underwriting decisions and the medical reasons behind them. In 1902, the Rejections Exchange was replaced by an exchange operation under the Association of Life Insurance Medical Directors. Then, in 1947, it was reorganized as an independent, unincorporated group. The present MIB considers itself essentially an extension of members' underwriting files, since it receives information only from these companies.[54]

For about 60 years, the MIB was a manual, card-index operation. It went to computerization in 1970, but this has not made any difference in the kind or amount of information the bureau maintains.

Information about an individual received in connection with insurance applications is sent by a member firm to MIB's Boston office. These reports appear as a list compiled from MIB's "Official Code List of Impairments." The code, which is confidential, covers a broad range of health conditions and certain non-medical factors. Both favorable and unfavorable information is reported.

The MIB stresses that its records are not complete medical histories. An average report consists of fewer than three coded entries. It does not include documentary records such as physicians' or hospital reports. Files may contain data about conditions like heart trouble and may note results of x-ray and glucose tolerance tests. Each separate report is killed from the data bank seven years after being entered.

After passage in 1970 of the Fair Credit Reporting Act, the MIB voluntarily made several changs in its procedures. Medical information is exempt from the FCRA, but the bureau offered to comply with it anyway, and claims to do so "insofar as notice, disclosure and disputed accuracy are concerned."[55]

But during the 1973 hearing on proposed FCRA amendments, the MIB came under fire for failing to make sure insurance applicants know that information about them might be reported to the bureau. In addition, the Senate committee criticized MIB for maintaining certain sensitive personal information. A procedure then was established to inform applicants to all member companies of the MIB's existence, of the possibility of a report being made to MIB and of the availability of disclosure and disputed accuracy procedures. And the group eliminated the use of codes for such items as "sexual deviation" and "social maladjustment," along with other non-medical codes.

The policy changes, made in 1974, allowed insurance applicants to get information in their record by requesting that it be sent to their insurance company. It would then be passed on to their doctor who would review it with them. Corrections could be made in conformity with the FCRA.

In 1975, the MIB amended its rules to give persons direct access to their non-medical records as long as they provide identifying data and a history of previous insurance applications. But medical information still is given only to an individual's doctor. And those persons wanting to see their records with MIB must sign a release freeing the bureau and its member companies from liabilities or damages in connection with the records.[56]

Information-keeping practices in the insurance business have continued to elicit criticism from government and others, however. In 1976, the President's Privacy Protection Study Commission conducted hearings in which it explored, among other matters, the incidence of MIB members initially reporting inaccurate or incomplete information. Although the bureau now has special procedures for monitoring reported information, the accuracy of its data continues to be suspect.

The FCRA requires a party to reinvestigate challenged information about an individual. MIB claims to conform with all such requirements, but the process is long and problem-laden.

When a person wants to challenge information about himself kept in MIB records, he must first obtain from the Boston office a "Request for Disclosure" form. "When that has been returned to the Boston office, they will make the necessary arrangements for disclosure of medical information through the individual's designated physician and disclosure of non-medical information to the individual directly," says William R. Swarts III, the MIB's associate general counsel.[57]

One criticism that has been leveled at the MIB concerns the investigation of medical or other problems indicated in bureau records. The codes appearing in records are intended to simply alert member companies to factors that might affect an individual's rating as an insurance risk. But often companies flatly reject applicants on the basis of MIB reports alone, without doing any further research, according to the **Privacy Journal**.[58] Individuals may be denied insurance on the basis of erroneous data contained in their MIB record unless they are able to get access to the information and audit it.

OSHA Proposal: Worker Access to Medical Records

If a set of guidelines proposed last July by the Occupational Safety and Health Administration is adopted, workers exposed to hazardous substances on the job will gain the right to see their medical and exposure records maintained by the company. Much debate has surrounded this proposal. In addition to the worker-access rule, the provisions allow OSHA and the National Institute for Occupational Safety to see all corporate medical records without prior notice to the worker.

Under the suggested rules, employees can see and copy all "relevant" records of past, present and potential exposure to toxic substances in the workplace, and see their full medical record, which may contain personal and family information (some of which may have been provided confidentially by third parties).[59] Employees would even have access to the exposure records of all other employees kept in a "log of job-related injuries and illnesses" required by OSHA.

Spokesmen from the American Iron and Steel Institute

have challenged the proposal on the grounds that allowing workers to see their medical records exceeds OSHA's authority as granted in the Occupational Safety and Health Act of 1970. The act specifies that a record can be given only to certain federal officials after an employee asks his doctor to release it, they said.[60] But OSHA asserts, in its proposal published in the **Federal Register** July 21, 1978, that employees, former employees and their designated representatives have a basic right to know about their exposures to workplace hazards and the effects of exposure.[61]

> The goals of occupational safety and health are not adequately served if employers do not fully share the available information on toxic materials and harmful physical agents with employees. Until now, lack of this information has too often meant that occupational disease and methods for reducing exposures have been ignored and employees have been unable to protect themselves or obtain adequate protection from their employers.[62]

The Department of Health, Education and Welfare, which cooperated with OSHA in issuing the proposal, estimates that 880,000 American workers are exposed to hazardous substances in the workplace.[63]

In public hearings held in Chicago, San Francisco and Washington, D.C. this past December and January, workers testified that they needed access to their medical records so they could learn more about workplace hazards. "Such information is already accessible to management," it was noted. George Becker of the United Steelworkers cited a case in which employees at an Indiana smelter were exposed to potential lead poisoning. The company possessed information on blood lead levels and chelations therapy, but didn't release it, claiming the information was confidential.[64]

At a Patients' Rights Conference in Atlanta, March 14-15, Grover C. Wrenn, OSHA's director of Health Standards Program, cited testimony from workers that "if they had only known about the toxic effects of chemicals to which they were exposed, they would have either declined hazardous work assignments or adopted protective measures to control their exposure."[65]

NCCHR director Eloise Agger, of the Federation of Societies for Clinical Social Work, said giving employees access to their health records would help rid the job atmosphere of distrust and act as a check against violations against confidentiality.[66]

Speaking against the proposal during the hearings, representatives from the American Medical Association argued that such access would violate the privacy of doctor-patient relationships. In addition, they said, it would violate big business' right to confidentiality; workers might misinterpret information in their records, and the increase in processing would increase administrative costs.[67]

Modification of the OSHA rules was urged by Dr. Bruce Karrh of Du Pont. Health records, he said, should be kept under the control of a physician, who can disclose information from them to employees on the basis of their need to know. If the OSHA regulations were adopted in their present form, they "would undermine employee confidence in and professional control of occupational health programs," he said.[68]

Robert Belair of the NCCHR urged a similar compromise. He suggested the use of a second health professional — a middleman — between patient and record in cases where direct access might cause psychological damage to the patient.[69]

It is likely that the OSHA guidelines will be enacted (though probably not before 1980, according to Dr. Patricia Buhl of OSHA), but industry probably will try to restrict the provisions. As it stands, the rules give employees virtually unlimited access to their own records. The proposal specifies that medical and exposure records should be kept by companies for the duration of employment plus five years. Employers must brief workers annually on the whereabouts of their health records, and inform them of their right of access.

Conclusion

From the variety of views, laws and practices presented here, it appears there is no consensus on the wisdom of granting individuals access to their medical records.

Doctors and other health professionals generally favor the exercise of discretion and judgment on the part of the treating physician as to whether a patient should receive his record, although there is a trend toward granting access.

When third parties like insurance companies and employers keep medical information on an individual, that person needs to make sure the records are accurate.

Groups like the MIB, if they allow access, usually have a complicated procedure for obtaining information in a medical record. Since such groups share information with so many others — information that can affect an individual's life opportunities — the government has expressed concern with them. People are urged to seek periodic access to their records for the purpose of checking them.

Laws and regulations now being discussed, like the OSHA proposal, highlight the increasing demand for personal rights, including the right to see and correct medical records. OSHA's concern with the rights of employees who might be exposed to hazardous substances in the workplace illustrates the seriousness and the controversiality of this issue.

On April 2, President Carter submitted to Congress a privacy bill that includes the Privacy of Medical Information Act. According to the President,

> Individuals should be told what kind of information is being collected about them, how it will be used, and to whom it will be disclosed. They should be able to see and obtain a copy of the records and correct any errors. They should be told the basis for an adverse decision that may be based on personal data.[70]

Under the proposed act, a doctor or other party does not have to release a health record to a patient when he fears direct access may cause harm. The bill contains a provision to allow an intermediary to receive the information in that case.

Whether or not OSHA's guidelines are adopted and the Carter act signed into law, the fact remains that American citizens will continue to seek individual rights. These rights may carry with them disadvantages. There never will be total agreement on this issue, nor can there ever be as long as America consists of many different interests.

Whether or not medical record access for individuals becomes a concrete privilege, it promises to serve as a controversial stepping stone for the discussion of other rights among consumers of this country.

FOOTNOTES

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13. "Special Report: Summary of State Laws on Personal Privacy," **Access Reports** 2 (14 May 1976): p. 8.
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21. **Ibid.**
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24. Auerbach and Bogue, **Getting Yours**, p. 29.
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